

ISSUE BRIEF

Self-Determination and Self-Advocacy by People with IDD

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People with intellectual and developmental disabilities (IDD) have the capacity to make choices and express preferences, solve problems, engage in making decisions, set and attain goals, self-manage and self-regulate action, self-advocate, and acquire self-awareness and self-knowledge. Such actions, known as self-determination, emerge across the lifespan and the value of developing these skills is endorsed in public policies concerning education, health, employment, and community-living for people with IDD. However, research is necessary to assure that practices and interventions support optimal skill development and self-determination outcomes.

► Introduction

Over the past 25 years, changes in the field shaped by the self-advocacy movement and social-ecological models of disability have led to an explosion of research on self-determination. While the notion of the inherent capacity and fundamental right of all people—including people with intellectual and developmental disabilities (IDD)—to be self-determining is relatively new, the civil rights and self-advocacy movements have played a critical role in shifting power to people with disabilities and enabling person-centered, self-directed supports that promote self-determination (Wehmeyer, Bersani, & Gagne, 2000). Self-determination has been identified as a right of people with disabilities in federal policy, and research has documented that self-determination status predicts employment and community participation outcomes (Shogren & Shaw, in press; Shogren, Wehmeyer, Palmer, Rifenshark, & Little, 2015; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997).

This brief describes the research goals identified by the invited participants of a strand charged with addressing self-determination and self-advocacy by people with IDD at the *National Goals Conference* in Washington, DC on August 6-7, 2015. The goals described here provide a vision for leaders in the self-advocacy movement, researchers, funding agencies, policy-makers, and practitioners for key considerations that must be emphasized to move the field forward and enable the conditions that support all people with IDD to lead self-determined lives.

► Need for Research

While self-determination is at the core of self-advocacy efforts by people with IDD and acknowledged as a goal by current disability policy and practices, research is needed to identify the most effective ways to develop and support self-determination within complex systems, identify practices that promote supports based on individual preferences, and to establish metrics to monitor and evaluate the success of related public policies.

► Support Need Research Goals

To assure that all people with IDD, including those with extensive support needs, will be self-determining, research is necessary to identify the most effective intervention strategies and to demonstrate that the practices can be successfully implemented in multiple settings. Inquiries to discover effective interventions employing universal design and addressing the needs of individuals with emerging communication skills will

enhance the capacity of service systems to support self-determination for all people with IDD.

► Technology Research Goals

To assure that individuals can advocate for themselves using

IMPACT

Tia Nelis, a leader in the self-advocacy movement and current president of Self-Advocates Becoming Empowered (SABE), describes the impact of self-determination and self-advocacy on the quality of life of people with IDD:

We (self-advocates) first need to learn how to advocate for ourselves. We have to be able to express what we need in our lives. If not, others will make decisions for us, and they won't be the decisions we want. As we grow and learn, we start also advocating for others and systems change and policy and legislation. This is the self-advocacy movement, and the most important thing is that it is controlled by the people.

It is also important for everyone to understand that self-determination doesn't mean that we will do everything on our own. We need support to help us live our lives. The key is that the support people understand that their role is to give us the resources and tools we need to make informed decisions, not take over.

For policy makers to support self-advocacy and self-determination, they need information to back up what we are saying. They want numbers and ways to prove that it is working. They want to know the difference that it is making. Research could give us this information if it is done in a way that involves people with disabilities from the very beginning. If we all work together, we will have good research, good policy, and good lives for people with disabilities.

existing and emerging technologies and in the online environment, research is needed to identify the most effective tools, strategies, and features, and to demonstrate that such strategies can be successfully utilized by people with IDD. Inquiries are needed in the following areas: to discover universal design features that are most important to promoting cognitive access and self-determination; the most effective strategies to teach and support technology use to enhance self-determination; and strategies that successfully involve self-advocates in the research and development process with technology companies.

► Training Research Goals

To assure that people who provide support across the lifespan (i.e., teachers, employers, direct support professionals, family

members) understand and enhance opportunities for self-determination of people with IDD, research is crucial to identify the most effective, culturally competent policies and practices and to demonstrate that those policies and practices can be successfully implemented in multiple settings. Inquiries to discover—across the life-span for people with IDD—the most effective strategies for training of support providers by self-advocates, policies and practices for promoting for self-determination in community environments, technologies for supporting self-determination, and strategies for scaling up self-determination interventions in all community environments, will inform policies and practices. In addition, research on the most effective strategies for supporting self-advocates to communicate their needs and wants is crucial to promoting self-determination.

► Solidarity Research Goal

Organizations led by self-advocates have begun to emerge; however, have been challenged in achieving financial independence, cultivating leadership, and developing infrastructure. Research to identify and evaluate best practices to advance the financial independence and capacity of self-advocates and self-advocate led organizations, with a focus on supporting self-advocacy organizations to build leadership, independent funding sources, and infrastructure would advance the principles of self-determination.

► Systems Change Research Goals

As states increasingly embrace the notion of self-determination in their IDD policies, research designed to identify effective systems of supports based on individual preferences and support needs is necessary to meet the mandates of policy. Inquiries are needed in these areas that can drive changes in future policy, research, and service delivery: to discover the impact of supported decision-making on the quality of decision-making outcomes; critical factors at all system levels that support or serve as barriers to developing self-directed supports; the impact of self-directed supports on the exercise of self-determination; and the most effective strategies to scale-up self-determination practices across organizational systems.

► Quality Research Goals

Research designed to elicit and evaluate self-determination strategies, metrics, and outcome data is essential to enable states and service providers to continually improve policies and practices and to facilitate the successful implementation of practices that support self-determination. Inquiries concerning people with IDD across the lifespan to discover validated assessments of self-determination, effective strategies to assess self-determination among people with extensive support needs, and critical environmental and contextual factors that impact

self-determination will drive changes in future policy, research and service delivery.

► Participatory Action Research Goals

To ensure that people with IDD are optimally prepared to participate in research about their lives, research is necessary to identify the most effective strategies to involve self-advocates in the research, planning, implementation, analysis, and dissemination phases of such research projects. Inquiries to discover methodologies that equalize the power dynamics in all phases of research, promote self-advocate involvement in the research review and application processes, and that could build a leadership pipeline of self-advocates with research literacy would enhance the validity of results of research on the lives of people with IDD.

► Conclusion

In order to continue to advance self-determination policies, practices, and outcomes in all settings, we must continue to refine and support effective practices to increase the expectations, assessment, participation, and achievement of people with IDD.

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